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ORIGINAL ARTICLE

VULNERABILITY OF CHILDREN EXPOSED TO FAMILY HUMAN IMMUNODEFICIENCY VIRUS

VULNERABILIDADE DA FAMÍLIA DE CRIANÇAS EXPOSTAS AO VÍRUS DA IMUNODEFICIÊNCIA HUMANA

VULNERABILIDAD DE LA FAMILIA DE NIÑOS EXPUESTOS AL VIRUS DE INMUNODEFICIENCIA HUMANA

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ABSTRACT

Objective: to analyze the vulnerability of the family of children exposed to HIV, from the perspective of family members. ***Method***: this is a qualitative study using the conceptual reference for family vulnerability to focus on key aspects on interviews with 16 family members of children exposed to HIV. In the data analysis, a deductive content analysis technique was used, using the defining elements of family vulnerability concept. ***Results***: after the process of analysis, five categories emerged: << Being under the impact of the discovery of HIV >>; << Stigma and fear of transmitting HIV to the child >>; << The existence of family disputes >>; << The prejudice of staff and lack of social support >>; << Have the strength to fight in God and the child >>. ***Conclusion***: health professionals, especially nurses, should be committed to minimizing the elements that expose and increase the vulnerability of children´s families exposed to HIV. ***Descriptors***: HIV; Family; Vertical Transmission of Infectious Disease; Child Care; Nursing.

RESUMO

Objetivo: analisar a vulnerabilidade da família de crianças expostas ao HIV, sob a perspectiva dos membros familiares. ***Método:*** estudo de abordagem qualitativa que utilizou o quadro conceitual relativo à vulnerabilidade familiar para focar aspectos chaves em entrevistas com 16 familiares de criança exposta ao HIV. Na análise dos dados, empregou-se a Técnica de Análise de Conteúdo dedutiva, utilizando-se os elementos definidores do conceito de vulnerabilidade da família. ***Resultados:*** após o processo de análise, cinco categorias emergiram: << Estar sob o impacto da descoberta do HIV >>; << Medo do estigma e de transmitir o HIV à criança >>; << A existência dos conflitos familiares >>; << O preconceito da equipe e a falta de suporte social >>; << Ter em Deus e na criança a força para lutar >>. ***Conclusão:*** os profissionais de saúde, sobretudo, os enfermeiros, devem estar comprometidos para minimizar os elementos que expõem e intensificam a vulnerabilidade em famílias de criança exposta ao HIV. ***Descritores:*** HIV; Família; Transmissão Vertical de Doença Infecciosa; Cuidado da Criança; Enfermagem.

RESUMEN

Objetivo: analizar la vulnerabilidad de la familia de niños expuestas a VIH, sobre la perspectiva de los miembros familiares. ***Método:*** estudio de enfoque cualitativo que utilizó el cuadro conceptual relativo a la vulnerabilidad familiar para enfocar aspectos claves en entrevistas con 16 familiares de niños expuestas al VIH. En el análisis de los datos fue empleada la Técnica de Análisis de contenido deductiva, utilizándose los elementos definidores del concepto de vulnerabilidad de la familia. ***Resultados:*** después del proceso de análisis, cinco categorías surgieron: << Estar sobre el impacto de la descubierta del VIH >>; << Miedo del estigma y de transmitir el VIH al niño >>; << La existencia de los conflictos familiares >>; << El perjuicio del equipo y la falta de soporte social >>; << Tener en Dios y en el niño la fuerza para luchar >>. ***Conclusión:*** los profesionales de salud, sobre todo enfermeros, deben estar comprometidos para minimizar los elementos que exponen e intensifican la vulnerabilidad en familias de niños expuestos al VIH. ***Descriptores***: VIH; Familia; Transmisión Vertical de Enfermedad Infecciosa; Cuidado del Niño; Enfermería.

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INTRODUCTION

The advance of infection with human immunodeficiency virus (HIV) has raised not only more than people living with HIV, but families affected by the virus.[1] The incidence of the disease in women of reproductive age enabled the birth of children with HIV due to vertical transmission (VT).[2] Therefore, over the years, a series of behaviors to potentially reduce this transmission has been established and expanded, particularly in Brazil, as tests, provision of antiretroviral therapy (ART), caesarean section and replacement of mother´s breastfeeding.[1] Besides having to deal with these measures to prevent the VT, the family is still dealing with other aspects of living with the disease[3] and the risk of a new generation of stigmatized and vulnerable children due to HIV.[4]

With the diagnosis, the family experiences a process initially unknown, accompanied by feelings of disorder, uncertainty, guilt and helplessness that gradually is transformed from its reorganization.[5] The family plays a fundamental role in the treatment for the prevention of VT and is a complex object of study that can be seen from various aspects, considering relationships of consanguinity, adoption, custody or marriage or defined as a group of people living together or having strong emotional ties.[6] From observing the family background and how its members are affected by the virus, it is possible to realize the complexity involved in the process experience of being a child family member in the presence of HIV.

Nursing should promote care actions not only for the child but also the people living with HIV. This is due to the responsibility of the family for the care, which suggests the need to receive aid and support.[3] Thus, it is necessary to know the functioning, structure and family needs.[7] HIV involves areas as physical and mental health, disease transmission, social relationships (including marriage), and challenges about dealing with stigma and discrimination, with the disclosure of HIV status and management of HIV as a chronic and infectious disease. There are also the predictable challenges related to the age of development of families, living situation or stage of the disease.[1] These aspects refer to vulnerable situations and to think of the family vulnerability involves questions that go beyond the individual, covering the context of the disease and the interactions of its members.

The emergence of families who experience the care of children in the presence of HIV from the perspective of family vulnerability is still little explored. There are limitations to the use of this theoretical reference for its recent use in the context of HIV/AIDS.[8] About a decade ago, the familiar concept of vulnerability was not precisely defined in the literature. Thus, studies have been done to develop it into disease and hospitalization of their child situation. Thus, the definition of vulnerability for the family denotes threat to their autonomy, in a context where the family feels pressured by the disease, by other family members and the health staff.[5] Based on this concept, the objective is to analyze the family's vulnerability children exposed to HIV, from the perspective of family members.

METHOD

This is a descriptive study with a qualitative approach, enabling to understand the phenomena focused from the subjectivity, allowing the deepening of knowledge about beliefs, values, actions and relationships of human beings.[10] The conceptual reference of vulnerability of the family under its perspective, in sickness and hospitalization of the child situation, was used to guide the research, to identify key aspects of the background, attributes, and consequences, being concept axes under study.[9]

The background or past experiences can trigger the vulnerability and are characterized by demands accumulated affecting a family´s ability to handle the situation. The attributes define the vulnerability and are related to a) the context of the disease characterized by various feelings such as grief, fear, sadness, impotence, threat, and expectations; b) familiar scenario that can function impaired with the emergence of conflicts and changes in family life; and c) hospital setting with crises in the interaction with health professionals. As a result, there is the transition between moments of the concept of autonomy with moments of powerlessness in the family that gives dynamism to the feeling of vulnerability that can be continuous along the child´s disease and hospitalization experience.[9]

This conceptual proposition was used to understand the family´s vulnerability in a context of care to children exposed to HIV. Family members responsible for the care of children exposed to HIV were interviewed, with a total of 16 participants (eight family dyads), comprising eight mothers, five parents, two grandparents and an aunt. Family affected by HIV selected should have: 1) Child: Daughter diagnosed with HIV positive, age up to 18 months without the full

definition of virus infection (infected or not infected/serum reversed) and to pediatric care in specialized care service (SAE) in HIV/AIDS; 2) Family Member: being the child´s primary caregiver role and therefore knowing his vertical exposure condition, and accompany the child in outpatient visits periodically.

The choice of the child-age group was due to the care provided to reduce the risk of vertical transmission and still not be possible to indicate the conditions of the definitive diagnosis, given the need for compliance with serologic evolution. Besides, this is a follow-up period of tension and expectations for the child´s treatment and disclosure of his diagnosis.[11]

The research field stage took place from December 2012 to February 2013, in a health institution in a city in northeastern Brazil. This location was opted to be characterized as a state center and another surrounding reference, for the care of Sexually Transmitted Diseases (STDs) and HIV/AIDS, having one SAE where children are outpatient.

Families and family member who held the child's primary caregiver role were identified, according to the child's records description and reporting of health professionals. In the waiting room for child consultation, the family member (usually the mother) was approached and asked to go to a private room, who was consulted on the agreement to participate and to invite other family members. At that time, they were informed about the purpose and data collection strategy. If mothers agreed to participate and were accompanied by another family member (parent, grandparent or child's aunt), they were invited to participate. Thus, it was sought to preserve the intimacy, the mother´s autonomy and confidentiality of the report and/or their HIV status. After signing the Informed Consent Form statements, they were taped and recorded.

For data collection, the press conference with unique meetings was used, which lasted on average 50 minutes. To identify the family vulnerability context, family members were asked about the difficulties faced about treatment, the disease, the family and the health team from the birth of the child, as well as the decision-making regarding treatment and care of the child exposed to HIV.

For the data analysis process, the deductive content analysis was used that is used when the analysis structure is implemented based on previous knowledge.[12] After the full transcript of the interviews and several readings to get the sense of the whole, a structured matrix composed of the background elements, attributes was used, and therefore composing the family vulnerability concept.[9] The data have been encoded according to a structured matrix, that is, only aspects that are set based on the array elements that identify the family´s vulnerability were chosen data. Thus, from the aspects of the data that is embedded in the matrix, it was possible to organize them and name the categories of the study, as shown in Figure 1.

To preserve anonymity, family dyads were identified by the letter F followed by a number representing the entry order in the study and who produced the speech. Thus, F1 parent is speaking of the mother and the first dyad interviewed and F8-aunt, speaking aunt and the last dyad. This research followed all legal and ethical precepts of the National Health Council Resolution 196/96, in force at the time of preparation and execution of the project, and had a favorable opinion of the Ethics and Research Committee of the Federal University of São Carlos/UFSCar for its realization, with the CAAE: 01922512.2.0000.5504.

RESULTS AND DISCUSSION

The study included eight families of children exposed to HIV, represented by five dyads mother and father of the child, two dyads mother and grandmother and a mother and aunt dyad, totaling 16 participants. As for the family setting children, three of them lived with their mother and father, three with the mother, father, and brothers; one lived with his mother, grandmother, and brother and one lived with his mother, the maternal grandmother, sister, cousins, and aunts. Five children had seroconcordant parents; two had serodiscordant parents, and the father of a child had not performed serologic testing until the time of the interview. In six families, the child was the first case of vertical HIV exposure and two families the second case of exposure. In all families, the mother held the prenatal and used HAART during pregnancy. In most families, the mother (five) discovered the disease during pregnancy, two before pregnancy and one during the birth of the child.

From the matrix structured with elements of families[9] vulnerability conceptual reference, it was possible to learn the family vulnerability of experience caring for children exposed to HIV and five categories were defined: Being under the impact of the discovery of HIV, Stigma and fear and of transmitting HIV to the child, The existence of

family conflicts, The prejudice of staff and lack of social support and Have the strength to fight in God and the child, as Figure 1.

Family vulnerability experience			
Structure Matrix	Background	*Categorizatio*	• Being under the impact of the discovery of HIV
	Attributes		•Stigma and fear and of transmitting HIV to the child •The existence of family conflicts •The prejudice of staff and lack of social support
	Consequences		• Have the strength to fight in God and the child

Figure 1. Categorization arising from the experience of families of children exposed to HIV, according to the conceptual reference of family vulnerability.

♦ Being under the impact of the HIV discovery

The family in the care of children exposed to HIV vulnerability experience and rescues in this previous experiences: the discovery of HIV period. The surprise against the unexpected diagnosis of HIV seropositivity impacted the family who did not know how to deal with the new situation, generating negative feelings tied to the idea of the finitude of life. All inherent lack experience with the disease.

> *When she [wife] knew [of the disease], for her and me it was a shock. It is as if to say, a person who died! (F4-father)*
> *It was very difficult for me. We had no experience with it; it was the first case in the family. There were people who said it would pass [the suffering], but we think he will die. (F2-grandmother)*

The discovery period of the disease and the meaning of diagnosis, as well as the different reactions, have also been found in other studies.[4,13-4] In addition to the impact of the diagnosis, the family was faced with unknown needs and was not always adequately prepared to act with the disease because they were unaware and did not know why the therapeutic care to be provided to the child to lessen the chance of VT.

> *With her [first child] it was more difficult because it was all of a sudden. I did not know what it was [HIV]. They said to bring the baby here [Specialized Service] after the birth and reported on the medication she had to take over a month and we could not miss any day. I do not know why all this. (F7-mother)*

The difficult relationship with the team that does not guide or inform the family causes a propensity to vulnerability. The very lack of information generates feelings of insecurity, uncertainty and accentuates the unpreparedness to act, leading the family to the condition of vulnerability[13] and related stigma to HIV.[4]

♦ Stigma and fear of transmitting HIV to the child

As the family vulnerability, conceptual reference, vulnerability is expressed in different contexts: illness, family system and team.[9] In the context of the disease, this study brought that living with HIV or with the risk of having a child living with HIV made the family feel threatened by fear of discrimination. To avoid this, they reduced the number of people with whom they shared the diagnosis, informing only the family:

> *Our biggest concern is the discrimination by others. Maybe it is just the family and few more. Relatives and second-degree relatives do not know it. Only we know. (F4-mother)*

There were families, whose mother did not disclose the diagnosis to the partner/father of the child for fear of not being understood, of being blamed or suffer physical violence.

> *She [daughter] should have said [about HIV] before he had a son with him [partner], to have "attached" to him. He disrespects. I am afraid to tell him [son in-law] [...]. There are many people who get the news and has nothing; there are others who are aggressive and even kill. (F8-grandmother)*

The literature shows the stigma associated with the diagnosis of HIV and fear of social isolation to share the diagnosis.[4,15] There are also gender issues that permeate the relationships in the context of this disease.[2] A study of women living with HIV shows that many of them do not reveal the diagnosis even to their partners for fear of suffering prejudice given the stigma attached to disease.[16]

The family is afraid of being exposed, especially in the neighborhood, and health professionals to disclose the diagnosis to others. Despite the existence of professional secrecy, she feels insecure and fears of being judged and discriminated:

> *Because we do not want to know, even at the place where we live has a lot of known people. Despite knowing that professionals cannot comment, but we think that it can happen, that they should be commenting. (F5-father)*
> *I had to ask for a referral to the doctor. I said I had HIV and I had to take it [child] in infectious disease. I was afraid, ashamed that they should be making critical or*

telling the staff, suffer discrimination. (F1-mother)

Discrimination by the health team affects the follow-up of children and attention to family needs, which ultimately move the people away from the service.[17] The literature suggests that the lack of trust in health professionals is partly for having suffered earlier with professionals from different health services inadequate attitudes that led to distrust of professional ethics and insecurity reveal diagnosis.[18] in this study, it is highlighted the background related to the discovery of HIV and poor interaction with health professionals made the family bring the current experience highlighting their vulnerability and distrust of the professional.

The care not to transmit HIV to the child was emphasized by families in the home environment. A person living with HIV is perceived as a threat to the child, and the fear of transmission makes the family establish limitations in daily life with the child.

I care about him [child], I try to avoid taking it when I am menstruating. I wanted to ask about it. I am afraid to go to the bathroom to change the absorbent and then take it. (F1-mother)

I am afraid of my blood to contact her. I take great care. Her clothes are washed separately. Because beyond the disease, you must be careful. The bottle I always wash the dishes separately. I take care. (F5-mother)

Feelings of apprehension, fear, and guilt of being responsible for the possible transmission of HIV to the child caused physical detachment from the mother to the child. These feelings are so impactful that studies of women and their partners about the decision by the pregnancy revealed that many of them living with HIV do not wish to have children, for fear of transmitting it to their children and feel guilty.[19, 20]

Despite knowing about the modes of transmission, the family feels threatened by the presence of HIV and prejudice:

I am apprehensive; sometimes I deprive myself of having a closer contact for fear. I think so; he has nothing, so anything was me [that transmit HIV]. As much as the doctor explains, we always have that apprehension. Because prejudice is not only other people, we have prejudice us. (F6-father)

It was highlighted the prejudice arising not only from others but them, and it has also been found in other studies, in which prejudice can from the very person.[4,21]

♦ The existence of family conflicts

In addition to dealing with HIV, family experiences internal conflicts, as manifested by alcohol involvement, lack of communication and perception of selfish attitudes of other family members. Worry and loneliness not to have other family members nearby were also highlighted, as well as conflicts in marital relationships.

Who suffered was me. I was worried about him [partner], not sleeping at night. I was anger, that desperation. Because he said, I go here, and I will be back, and he just arrived in the morning. He was out for drinking. I even commented that he has all his family on his side and I did not, despite all being very good to me. (F7-mother)

I worry about all this [child care] and with my husband. It does not give me more attention. After he had learned that I was [HIV], I think he changed [silence]. I never spoke to him about it (F1-mother).

The study shows that the use of alcohol and some types of aggressive behavior within the family cause conflicts stressful for all family members.[15] It also interferes the continued use of HAART and following the specialized service.[4]

The moment the family is living interferes with relationships, giving rise weaknesses, misunderstandings and difficulties in communication. There is stress find that the other does not care about the condition of living with HIV and not seeking information about the disease, as well as rise and past conflicts frustrations.

My biggest stress is because I fight with her [sister HIV+] to her go after information to be reading, watching, but she does not go after information about the disease or what happened. She does not understand, but I am just wondering because of her [...]. After she got the virus, I have researched everything about HIV, and she did not go after anything. (F1-aunt)

She is very nervous [daughter HIV+] speaks a lot to me, is rebellious. I suffer a lot from it. It is like she unloaded everything in me. Always gave me work even after marriage. It hurts me a lot. I think she was the "bird that did not fly." (F2-grandmother)

The family undergoes changes in its structure and functioning to experience the context of the disease and its impact, causing loss of control. Studies point to the reorganization of the structure sociofamiliar[3] and the family need to be assisted in their reintegration and even points the partner/father of the child as an important resource in helping the mother to prevent VT.[2] The need to organize in favor of treatment of children and the demands arising

cause overload and subsequent internal conflicts that intensify the vulnerability and provides the removal of some family in view of the disease to be reckoned.[8,9]

♦ The prejudice of staff and lack of social support

Interactions with the healthcare team during and after the birth of the child were accompanied by conflict. The lack of dialogue and information on procedures and child's test results pervaded the relationship between professionals and family, giving way to doubt, fear, feelings of neglect and lack of preparation to deal with the situation. As the conceptual reference, these feelings together characterize the vulnerability of the family.[9]

> *He [child] made two blood tests and never said anything if he had anything or not. After just said to take this medicine [oral AZT]. I thought: is he taking this medicine because he is infected? Will they not give me the examination, something? No one ever said anything to me, when I asked one was "pointing" to the other. (F6-mother)*
>
> *[In maternity] Medication was also so, the difference is that they left the syringes prepared with the drug in the infirmary [...]. I put the phone to tell the time and gave the medicine. They [nurses] do not even come to say; it is time. (F7-mother)*

There was prejudice by the health team, generating feelings of exclusion, powerlessness and disrespect in families, making them more vulnerable:

> *She [mother HIV+] suffered a lot [...]. I noticed that my daughter was not answered as she deserved to be. They said they had no vacancy, but we knew we had one more reason because they looked at her file. She was excluded! She was barely in his delivery [child] because it took forever to be served. (F2-grandmother)*
>
> *I said I was [HIV]. [...] I saw they looked like she [health professional] was so with "disgust" or fear of taking me there in the maternity. (F3-mother)*

Families have not been accompanied by the healthservices[4] and ideas that motherhood is threatened for women living with HIV often are present among health professionals.[21] The study reveals that many women despite the presence of HIV desire pregnancy and most never discussed this during the consultations.[20] Some reported having experienced some form of discrimination in the health service, and with doctors specializing in HIV that discrimination occurred most frequently, followed by family physicians and obstetricians/gynecologists.[20]

The lack of social support or failure of it associated with the shortage of family financial resources put at risk the health of the child, the follow-up treatment, and adequate food. Also, it caused concern in the family and feelings of helplessness, guilt, and contempt, due to the interruption in the distribution of artificial milk, their distribution outside the period of validity and the impossibility of mother´s breastfeeding. In this context, family members tried to help by supporting:

> *She [daughter HIV+] has had much trouble because of the lack of children´s milk. Others, aunts, who are giving. Since she gave birth, she cannot give breast milk so it 3 in 3 hours, and we are very worried. We have three months without receiving free milk, and we are not able to buy it. (F2-grandmother)*
>
> *[...] We gave some tea a couple of days for her [child] and continued to purchase milk and mixing, but it was another milk. We give her that to the other gets here. (F8-grandmother)*
>
> *When we went to pick up the milk, it was packaged in a box. The man did not look up, and when we got home, we saw they were all spoiled. (F4-mother)*

Difficulties with the displacement, about the cost of public transportation to the specialized service, were also part of this vulnerability context:

> We had to ask for money to come here. [specialized service] (F7-father).

The financial and social implications for the treatment and monitoring of children may prevent the successful actions to prevent VT. Studies show relatively little support perceived by couples living with HIV[20] and the influence that social relationships in the desire for pregnancy.[22] Lack of social support undermine the household well-being as it fills the family of despair and difficulties to proceed with the treatment. A limited support network can be considered as a factor that leads to family vulnerability, creating obstacles for the acquisition of resources for treatment, aggravated by poor financial condition.[9]

♦ Have the strength to fight in God and the child

With the vulnerable situation, the participating families have sought strength in God and the child to overcome and reframe everything that has lived to change the situation. The families have shown a strong relationship with God and believed that through faith they could reach the negativity of HIV in children:

> *I sincerely hope that it is healthy and does not need to do this treatment we do a lifetime. I just pray to God every day that*

she does not have this disease that we have. (F5-father)

I believe that he [son] has nothing because I believe in God. I am sure it will be negative on the next exam. I am not afraid of the result. (F6-mother)

Seeking to change the situation confirms the structured matrix of the conceptual reference of family vulnerability, characterized as a positive consequence of vulnerability. The feel threatened in their autonomy, characteristic of vulnerability, encourages the family to get out of this condition, to seek strength and regain control of the situation affected the relationship with the team, the family itself and the disease.[9]

The findings in the testimonies were also mentioned in other studies, in which God was the most important source of supporting the family. By faith in God, they believe they can achieve healing, comfort, and conformity.[3,23] However, the family condition characterized by the child's follow-up with periodic examinations to confirm the diagnosis[5] and the fear turn out to be soropositive[11,21], brings this experience transitory nature of vulnerability and the possible weakening of spirituality.

The vulnerability consequences are dynamic, sometimes strengthening and sometimes weakening, understood as negative and positive.[9] Negative when the meaning points to guilt and suffering resulting from the acts of themselves and of God´s action. These feelings and the belief that the disease was God's punishment was also mentioned by other authors.[17]

I was always negative. I think of divine punishment. [...] For our failure, she became pregnant; the news of the pregnancy was like a punishment. I kept thinking; I will be punished by a child with HIV because I did much wrong in the past. (F7-father)

The child was also seen as a source of strength and hope. The desire to look after the children made the family member with HIV want to live and do the treatment. Apart from that, the child also became associated with the discovery of HIV, as if she had come with a mission to warn parents about the disease.

It was a very big impact because at the time we think much nonsense. They [children] gave strength to us; that was not the end of the world. (F5-mother)

I am just doing this treatment for my children, because if I do not take care of them who do not have to. To have, but it is never as the mother. (F7-mother)

He [child] came to tell that something was wrong. When we look at it, we have that sense of hope, medicine. (F6-father)

The affection I have for the mother and child after discovering the disease has only increased. (F4-father)

Studies show the importance that the child takes for parents in addressing the health-disease process, which women decide to fight for life and not taking medication for the care of herself but to be able to take care of their children.[16] This child support can be realized from the gestation.[18]

The search for understanding and reason by the suffering experience is also a way of coping, in which they try to have a meaning.[23] Despite not satisfied with the diagnosis of seropositivity, there is a readaptation and the search for new paradigms for the quality of life and health.[25] Thus, with the search for meaning and reframing, the family seeks its autonomy.

CONCLUSION

The conceptual reference of family vulnerability concept enabled the understanding of children with families' experience exposed to HIV and explored the various elements that expose and enhance their vulnerability. Although the structured matrix (antecedents, attributes, and consequences) have been developed with families with child in illness and hospitalization situation, its applicability in the home context of care to children exposed to HIV showed common elements and others that have been expanded due to hospital context that this study was not very experienced.

The results showed defining aspects of the concept, especially the loss of autonomy triggered in the family sphere, in the context of HIV and the relationship with the health team. The child care experience has shown moments when families seek to recover control of the situation and minimize their vulnerability. The stigma of the disease, fear of HIV transmission to the child, family conflicts and the lack of support from health professionals were highlighted in the characterization of vulnerability.

From these findings, health professionals may recognize the family situations of vulnerability and exploit positive coping elements of the disease and treatment of children, as well as realize the insertion of nursing in this context and its potential to minimize the suffering and vulnerability of families.

The limitations of this study were the data collection strategy held before the child consultation, which left some anxious mothers, and the difficulty of interviewing other family members, not knowing the HIV status of the mother and the reason for consultation of the child. For future research, other family members and intervention studies have to be included to help families in vulnerable situations deepen the knowledge of this subject, opening the way for the work of nursing.

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